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236 A review of the use of the PEP mask in screened infants – a parent perspective

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Background: Since June 07 in Southampton, we changed our practice from using modified postural drainage and percussion (P.D/Perc) to using the PEP mask with all screened infants.
Method: Between Dec 07 and Jan 2011, 12 infants commenced on the PEP mask. As physiotherapists we found PEP an easy technique to instigate but wanted to review the parents experience. A telephone questionnaire was conducted to obtain their views. 9 out of 12 questionnaires were returned.
Results: The children's age range at time of questionnaire was between 10 months and 3 yrs and 7 months. 6/9 children were successful in establishing PEP and were continuing to use it. The majority were started on it between 3 and 8 weeks old. Two of the children not established on PEP started at 6 months old, which might have been a contributing factor to the lack of success. All 6 infants using the PEP mask, used it for the recommended frequency and duration and managed well. Out of a list of types of support/teaching offered, e.g. DVD of infant/toddler using the mask, home visits, peer contact/support, no one overall preference was seen. Interestingly 3/6 had experience previously using PD/Perc with a sibling and all preferred PEP. Of those continuing to use the PEP mask, the emphasis of the importance of early perseverence was crucial.
Conclusion: Overall the views were very positive and there was a good success rate of continuation. Probably equal to the success of any form of physiotherapy offered eg PD/Perc. Preference of the type of support varied individually so will need to be tailored to each family. Starting early at diagnosis helps with compliance problems and seems to be the key to success.

237 Modern physiotherapy for 0–7 years old at the CF centre Lund, Sweden

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Background: Physiotherapy is an important part of the CF treatment. It is time consuming and the treatment must be adjusted to the child's age and physical ability. Modern physiotherapy consists of inhalation therapy, airway clearance therapy, physical exercise including muscle strength, mobility, posture adjustment, body awareness, education and motivating to good adherence. The aims of modern physiotherapy are to prevent slow progression of the disease as well as acute exacerbation. The treatment has to be custom made for each individual patient since the symptoms vary. At present date there is a lack of updated documented information in Swedish about modern physiotherapy.
Objective: To design a booklet about modern physiotherapy dedicated for children 0–7 years old at the CF centre Lund, Sweden and to colleagues involved in CF cares at other local hospitals.
Method: Literature study and clinical experience.
Results: The literature study proved that the treatment and the physical therapy regime that we offer CF patients in Sweden has given good results in survival, preserved lung function and working capacity. A booklet was produced including information about prevention, specific needs and photographs showing examples of therapy contents and exercises suitable in different ages.
Conclusion: Initial patient feedback has been extremely favourable. We believe that the booklet will help the parents and our colleagues to perform the most optimal physiotherapy regime for each individual.
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238 Paediatric physiotherapy review following the introduction of newborn screening in cystic fibrosis

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In line with the UK Delphi consensus and the introduction of newborn screening, traditional intensity of airway clearance techniques (ACT's) has no longer been advocated in asymptomatic babies with cystic fibrosis (CF) at this centre. Parents are taught ACT's (modified postural drainage and percussion), to assess their child appropriately and treat according to respiratory symptoms. The specialist physiotherapists offer ongoing education, advice and support.
Aim: To review the physiotherapy management of newborn screened babies diagnosed between November 2006 and October 2009.
Results: 25 babies were diagnosed during this period. Median age of diagnosis was 3 weeks (1–20 weeks). All were reviewed by a specialist physiotherapist either on the ward (n = 8) or as out patients/in their homes (n = 17). Physiotherapy intervention began on day of diagnosis in 18 cases and within 3 days for the remaining 7. 18 families followed the new protocol. One chose to carry out daily ACT's due to parental anxiety and the remaining 6 required daily treatment due to symptoms or social issues. By 2009 11 babies had required hospital admission (mean 1.5), 10 for respiratory causes and 1 for nutritional issues. 5 babies had changed from intermittent to daily ACT's, all had isolated *Pseudomonas aeruginosa*. 3 required long term ACT's as symptomatic and 2 families wished to keep a daily routine. The remaining 13 continue to require ACT's intermittently.
Conclusion: Isolation of *Pseudomonas aeruginosa* was the main factor for patients requiring increasing intensity of ACT's in this cohort. However a significant number continue into early childhood without the burden of daily treatment.

239 Cystic fibrosis disease control improves patient survival in Latvia

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Objectives: As treatment of cystic fibrosis (CF) according to an internationally-approved therapy concept was begun in Latvia in 1993, it would be useful to establish the role of CF disease control in the CF patient survival increase in Latvia by performing an inquiry on the disease course and its control, and comparing the survival rate.
Methods: CF patient control inquiry questionnaire on the disease course, subjective and objective assessment of the patients' condition for 10 patients aged 7 and older. Latvian CF patients' survival analysis according to the Kaplan-Meier method [Armitage P, Berry G., 1994].
Conclusion: Part of the studied patients do not take prescribed medication on a regular basis or follow the recommended physiotherapy. From those having received no appropriate therapy (deceased by 1993; N = 122), the median of survival is 4.4±0.4 months. On the contrary, from the CF patients having received some kind of therapy (survived after 1993; N = 47) the median of survival is 20 years. If the 2008 and 2006 results are compared, the median of survival of the CF patients having received a therapy has decreased by 2 years. Compared to the median of survival of the CF patients having received no therapy, there is a pronounced increase in the median of survival of those who have. Only half of the CF patients are reminded to perform the necessary activities/exercises by their parents while a sole one is reminded to do additional exercises. The total number of cases: 169 patients (1961–2008). 27 CF patients are alive (16%), while 142 have deceased (84%).
Necessity of individual work with patients and their parents and boosting motivation is obvious.